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ABSTRACT

Context

Understanding the prevalence and characteristics of primary care outpatients being at risk of deteriorating and dying may allow general practitioners (GPs) to identify them, and initiate end-of-life discussions.

Objectives

This study aimed to investigate the prevalence and characteristics of primary care outpatients being at risk of deteriorating and dying, as determined by the Supportive and Palliative Care Indicators Tool (SPICT™).

Methods

A multicenter cross-sectional observational study was conducted at 17 clinics with 22 GPs. We enrolled all patients aged ≥65 years who visited the GPs in March 2017. We used the Japanese version of the SPICT™ to identify patients being at risk of deteriorating and dying. We assessed the demographic and clinical characteristics of enrolled patients.

Results

In total, 382 patients with a mean age of 77.4 ± 7.9 years were investigated. Sixty-six patients (17.3%) had ≥2 positive general indicators or ≥1 positive disease-specific indicator in the SPICT-JP. Patients with dementia/frailty, neurological disease, cancer, and kidney disease showed a significantly elevated risk of deteriorating and dying, while patients with other

specific disease did not. The patients at risk were significantly older and less likely to be living with family at home. They also had a higher Charlson Comorbidity Index score and a lower Palliative Performance Scale score.

Conclusion

Among primary care outpatients aged over 65 years, 17.3% were at risk of deteriorating and dying regardless of their estimated survival time, and many outpatients at risk were not receiving optimal multidisciplinary care.

Keywords: Identification tool, SPICT™, primary care, outpatients

Running Title: Risk of deteriorating and dying in primary care

Introduction

Most patients with chronic illnesses are managed in primary care over a long period[1]. Appropriate identification of such patients who may be at risk of deteriorating and dying would allow general practitioners (GPs) to assess them and identify the unmet supportive and palliative care needs of these patients and their families[2].

Assessment of unmet supportive and palliative care needs could also lead to initiation of end-of-life discussions among patients, family members, and GPs, which is essential for high-quality end-of-life planning[3–6], although GPs consider that they lack sufficient knowledge and skill to appropriately assess such unmet needs [7,8].

A recent study demonstrated that use of a systematic method or tool could facilitate efficient identification of patients who may be at risk of deteriorating and dying[9]. Several methods or tools have been developed for use in the primary care setting[10], such as the Gold Standards Framework Prognostic Indicator Guidance[11], Supportive and Palliative Care Indicators Tool (SPICT™)[12], Palliative Necessities CCOMS-ICO (NECPAL)[13], and RADboud indicators for PAlliative Care Needs[14]. A recent systematic review found that the SPICT™ is the most suitable tool for introduction and adoption in various primary care clinical settings [15].

The SPICT™ is designed to identify patients with chronic progressive diseases who are at risk of deteriorating and might benefit from palliative care. Unlike other methods or tools, the

SPICT is not restricted to specific diseases and has been tested in different settings (e.g. primary care, home care, and hospitals)[12,16–18].

Knowing the prevalence and characteristic of patients who may be at risk of deteriorating and dying in primary care should help GPs to identify such patients. Timely identification also could overcome the barriers to initiating end-of-life discussions[8]. Subsequently, GPs can organize appropriate care to achieve each patient's care goals.

Therefore, this multicenter observational study was performed to investigate the prevalence and characteristics of primary care outpatients who may be at risk of deteriorating and dying, as determined by the SPICT™.

Methods

This multicenter cross-sectional observational study was conducted at 17 clinics with 22 GPs in Japan. In March 2017, each clinic set an arbitrary day for each GP in advance and we enrolled the outpatients over 65 years old who were seen by those GPs on that day. This study was conducted in accordance with the ethical standards of the Declaration of Helsinki and the ethical guidelines for epidemiological research issued by the Ministry of Health, Labour and Welfare of Japan. The institutional review board of the University of Tsukuba approved this study (No.1089).

Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ was originally developed in Scotland and was based on the American National Health Observances guideline for eligibility of patients for hospice care combined with a further literature review and expert consensus input[19,20]. The SPICT™ consist of a combination of general clinical indicators (e.g. poor performance status, unplanned hospital admissions, or persistent symptoms despite optimal treatment of the underlying condition) relevant to patients with any advanced illness and disease-specific indicators for common advanced conditions (e.g. cancer, dementia, and cardiac, pulmonary, or renal disease).

The development, structure, and evaluation of the original English version of the SPICT™ have been described elsewhere[12], as well as its use as a guide to help physicians recognize people at risk of deteriorating and dying[17,18].

Development of the Japanese version of SPICT™

The Japanese version of SPICT™ (SPICT-JP) was developed according to an international standard translation and back-translation procedure[21]. The English-language items were initially translated by two native Japanese speakers who had experience with community palliative care and knew how words and phrases would be understood by general practitioners in Japan. Then

the two translations were reconciled by discussion. Any disagreements and unclear points were recorded, and we sought clearer explanations from the developer of the original version. The synthesized version was back-translated by a professional Japanese translator and the appropriateness of the English expressions was subsequently checked by a native English speaker. Then an independent professional proof-reader compared the completed synthesized version and the back translation, and provided comments. Subsequently, an expert panel with nine members (general practitioners with or without a special interest in palliative care, home care physicians, and palliative care physicians) reviewed the synthesized version. The final version of the SPICT-JP was developed by incorporating the comments of the expert panel.

Data collection

We recorded demographic and clinical characteristics of the patients, including the age, sex, living situation, main underlying disease, use of care services, and level of care needed[22]. We assessed the Charlson Comorbidity Index (CCI) score[23], the Palliative Performance Scale (PPS), and the 6 general clinical indicators and 25 disease-specific indicators in the SPICT-JP. (Appendix 1).

Statistical analysis

According to previous reports[24], we defined patients as being at risk of deteriorating and dying if they had ≥2 positive general indicators or ≥1 positive disease-specific indicators in the SPICT-JP. We calculated descriptive statistics for the prevalence of patients being at risk of deteriorating and dying. Characteristics of the participants were described as proportions for categorical variables and were analyzed by Pearson's $\chi 2$ test or Fisher's exact test, while continuous variables were analyzed by Student's t-test. In all statistical evaluations, a P value of less than 0.05 was considered significant. Analyses were conducted with SPSS-J software (version 24.0; IBM, Tokyo, Japan).

Results

A total of 382 patients were included in this study and their characteristics are summarized in Table 1. The mean age was 77.4 ± 7.9 years. Most of the patients lived at home with their families (78.0%), had a CCI score of zero (78.8%), PPS≥80 (79.1%), no certified care needs (75.9%), and no use of care services (81.4%). The most common main underlying disease was hypertension (31.9%), followed by dementia/frailty (15.2%) and cardiovascular disease excluding hypertension (9.2%). Only 2 patients (0.5%) used a specialized palliative care service.

Prevalence of patients being at risk of deteriorating and dying (Table 2)

The most common general indicator for a higher risk of deteriorating and dying was "The person or family asked for palliative care, treatment withdrawal/limitation, or a focus on quality of life" (25.4%). The major clinical indicator was "No longer able to communicate using verbal language; little social interaction" (n=23), followed by "Urinary and fecal incontinence" (n=13) and "Unable to dress, walk or eat without help" (n=12) in patients with dementia/frailty.

Characteristics of patients being at risk of deteriorating and dying (Table 3)

The characteristics of the patients being at risk of deteriorating and dying are shown in Table 3. Sixty-six patients (17.3%) had ≥2 positive general indicators or ≥1 positive disease-specific indicator. Patients with dementia/frailty, neurological disease, cancer, and kidney disease had a significantly higher risk of deteriorating and dying, while patients with other specific diseases did not. The patients at risk were significantly older than those not at risk, were less likely to be living at home with family members, and had higher CCI scores and a lower PPS. The care services used by patients at risk were mainly home nursing, home help service, and day care/day service.

Discussion

To our knowledge, this is the first large-scale cross-sectional survey investigating the prevalence and characteristics of primary care outpatients being risk of deteriorating and dying according to the SPICT™.

The first important finding was that 17.3% of primary care outpatients over 65 years old were at risk of deteriorating and dying. This was a much higher prevalence than that shown by a previous smaller study, in which the prevalence was 9.2% according to the SPICT™[24]. One possible reason for this difference was that our study was conducted at 17 clinics and enrolled the patients of 22 GPs, while the previous study was confined to a single clinic with one GP. Thus, our results seem to be more reliable with regard to the prevalence of patients in primary care who are at risk of deteriorating and dying. In addition, our prevalence was about twice that determined by a cross-sectional population-based study conducted in Spain, which identified 8.0% of patients over 65 years old with palliative care needs by using the NECPAL[25]. The NECPAL-positive patients were defined as positive for the “surprise question” (“I would not be surprised if this patient were to die in the next 12 months.”) and had at least one general or clinical indicator. Taken together with our result, it seems that a certain proportion of primary care outpatients are at risk of deteriorating and dying regardless of their estimated survival time.

The second important finding was that outpatients with dementia/frailty, neurological disease, cancer, and kidney disease had a significantly elevated risk of deteriorating and dying, while patients with other specific diseases did not. This finding suggests that outpatients over 65 years old with these diseases should be carefully assessed for the risk of deteriorating and dying. However, SPICT™ cannot identify patients with a risk of deteriorating cognitive function, although it evaluates the symptoms and behavioral disorders of dementia patients. Therefore, our finding that 67.9% of patients with dementia are at risk of deteriorating and dying requires careful interpretation. In the future, there is a need for a method that can evaluate the risk of deteriorating the cognitive function of dementia patients.

With respect to reviewing current treatment and care, primary care outpatients with dementia/frailty, neurological disease, cancer, and kidney disease could be regarded as a target population for active communication about the goals of care, such as "Jumpstart-Tips intervention"[26]. However, GPs often feel that they lack sufficient knowledge, skills, and experience to talk about existential needs, and may not actively ask about non-physical/disease-related care needs[27]. Thus, to improve the quality of active communication about goals of care, it is important to identify the multidimensional needs of patients and the kinds of conversations that occur among patients at risk of deteriorating and dying, family members, and GPs[28].

The third important finding was that almost half of the patients who were at risk of deteriorating and dying were not using a care service. This result implies that many outpatients at risk were not receiving optimal multidisciplinary care, which would be a barrier to initiating end-of-life discussions to achieve the care goals of patients. Thus, it seems important to implement systematic evaluation methods for identifying patients at risk and promoting interprofessional collaboration in primary care[29], such as the Gold Standards Framework in the United Kingdom[30].

It is noteworthy that only 3% of the patients who were at risk of deteriorating and dying used specialized palliative care. A retrospective study performed in the UK revealed that 30% of primary care patients were referred to specialized palliative care before death, although referral tended to be late and the median time until death after referral was only 4.9 weeks[2]. Since our study was cross-sectional, it is difficult to compare the frequency of referral to specialized palliative care. Thus, it would be worthwhile examining the level of palliative care delivered or offered in Japanese primary care practice in the future.

This study had several limitations. First, we only enrolled patients over 65 years old who

visited each clinic on a day selected in advance. Therefore, we only assessed part of the patient population who may be at risk of deteriorating and dying in each clinic. However, we minimized the influence of this methodology on the results by registering multiple doctors at multiple facilities. We consider that this approach is the most feasible for obtaining evidence in the primary care setting, although there is unavoidable sample bias. Second, our study was only carried out in Japan, although it was a multicenter investigation. Therefore, caution is needed when interpreting the results, which might be influenced by the Japanese health care system and cultural background. Third, observer bias might exist because assessment was conducted by the GPs of the patients. However, the SPICT™ was developed for assessment of patients by care team staff based on clinical indicators[12]. Therefore, observer bias should only have a small influence on the results.

In conclusion, among primary care outpatients over 65 years old in Japan, 17.3% were at risk of deteriorating and dying regardless of their estimated survival time, and almost half of those patients were not using a care service. To organize appropriate care to achieve each patient's care goals, it is important to determine what multidimensional needs exist and to implement a systematic approach for promotion of interprofessional collaboration in primary care.

Competing interests: The authors have declared no competing interests.

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Table 1 Patient background factors and characteristics (n=382)

		n	%
Age (mean ± standard deviation)		77.4 ± 7.9	
Sex			
Male		141	36.9
Female		241	63.1
Living situation			
	At home with family	298	78.0
	At home alone	59	15.4
	Care facility	8	2.1
Main underlying disease			
	Hypertension	122	31.9
	Dementia/ frailty	58	15.2
	Cardiovascular disease (not hypertension)	38	9.9
	Diabetes	30	7.9
	Hyperlipidemia	19	5.0
	Neurological disease	18	4.7
	Cancer	14	3.7
	Respiratory disease	13	3.4
	Musculoskeletal disease	8	2.1
	Mental disease	6	1.6
	Gastroesophageal reflux disease	6	1.6
	Kidney disease	5	1.3
	Liver disease	3	0.8
	Others	42	11.0
Charlson Comorbidity Index score			
	0	301	78.8
	1	35	9.2
	2	23	6.0
	3	3	0.8
	4	4	1.0
	5	1	0.3
	6	1	0.3
	7	2	0.5
Palliative Performance Scale			
	100	202	52.9
	90	51	13.4
	80	49	12.8
	70	20	5.2
	60	33	8.6
	50	22	5.8
	40	5	1.3

Level of care need		
no certified care need	290	75.9
Support need level 1	8	2.1
Support need level 2	11	2.9
Care need level 1	13	3.4
Care need level 2	14	3.7
Care need level 3	9	2.4
Care need level 4	1	0.3
Care need level 5	1	0.3
Current care services		
No care service	311	81.4
One or more care services	71	18.6
Type of care service (Multiple answers)		
home nursing	11	2.9
home help service	16	4.2
home pharmacist	1	0.3
day care/day service	54	14.1
specialized palliative care service	2	0.5

Table 2 Prevalence of patients at risk of deteriorating and dying

	n	%
General clinical risk of deteriorating health (n=382)		
Two or more unplanned hospital admissions in the past 6 months	1	0.3
Performance status is poor or deteriorating, with limited reversibility	24	6.3
Dependent on others for care due to physical and/or mental health problems	26	6.8
Significant weight loss over the past 3-6 months, and/ or a low body mass index	18	4.7
Persistent symptoms despite optimal treatment of underlying condition(s)	16	4.2
Person or family ask for palliative care, treatment withdrawal/limitation, or a focus on quality of life	97	25.4
Specific disease-specific risk for deterioration of specific conditions		
Cancer (n=14)		
Functional ability deteriorating due to progressive cancer	3	21.4
Too frail for cancer treatment or treatment is for symptom control	2	14.3
Dementia/ frailty (n=56)		
Unable to dress, walk or eat without help	12	21.4
Eating and drinking less; swallowing difficulties	9	16.1
Urinary and faecal incontinence	13	23.2
No longer able to communicate using verbal language; little social interaction	23	41.1
Fractured femur; multiple falls	10	17.9
Recurrent febrile episodes or infections; aspiration pneumonia	2	3.6
Neurological disease (n=18)		
Progressive deterioration in physical and/or cognitive function despite optimal therapy	7	38.9
Speech problems with increasing difficulty communicating and/or progressive swallowing difficulties	2	11.1
Recurrent aspiration pneumonia; breathless or respiratory failure	1	5.6
Cardiovascular disease (n=38)		
NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with: breathlessness or chest pain at rest or on minimal exertion	4	10.5
Severe, inoperable peripheral vascular disease	0	0.0
Respiratory disease (n=13)		

	Severe chronic lung disease with: breathlessness at rest or on minimal exertion between exacerbations	2	15.4
	Needs long term oxygen therapy	1	7.7
	Has needed ventilation for respiratory failure or ventilation is contraindicated	0	0.0
Kidney disease (n=5)			
	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health	3	60.0
	Kidney failure complicating other life limiting conditions or treatments	3	60.0
	Stopping dialysis	0	0.0
Liver disease (n=3)			
	Advanced cirrhosis with one or more complications in past year: diuretic resistant ascites	0	0.0
	Advanced cirrhosis with one or more complications in past year: hepatic encephalopathy	0	0.0
	Advanced cirrhosis with one or more complications in past year: hepatorenal syndrome	0	0.0
	Advanced cirrhosis with one or more complications in past year: bacterial peritonitis	0	0.0
	Advanced cirrhosis with one or more complications in past year: recurrent variceal bleeds	0	0.0
	Liver transplantation is contraindicated	2	66.7

Table 3 Characteristics of patients with or without an elevated risk of deteriorating and dying

	With two or more general indicators or one or more disease-specific indicators (n=66)		Without two or more general indicators or one or more disease-specific indicators (n=316)		
	n	%	n	%	p value
Age (mean ± standard deviation)	84.6 ± 7.9		75.9 ± 7.0		<0.001
Sex					0.858
Male	25	37.9	116	36.7	
Female	41	62.1	200	63.3	
Living situation					0.001*
At home with family	47	71.2	251	79.4	
At home alone	11	16.7	48	15.2	
Care facility	6	9.1	2	0.6	
Main underlying disease					
Dementia/ frailty	38	57.6	20	6.3	<0.001
Cardiovascular disease (not hypertension)	5	7.6	33	10.4	0.479
Neurological disease	7	10.6	11	3.5	0.022*
Cancer	6	9.1	8	2.5	0.020*
Respiratory disease	2	3.0	11	3.5	0.272*
Kidney disease	3	4.5	2	0.6	0.038*
Liver disease	2	3.0	1	0.3	0.078*
Others	3	4.5	230	72.8	<0.001
Charlson Comorbidity Index score					<0.001*
0	40	60.6	261	82.6	
1-4	19	28.8	46	14.6	
≥5	3	4.5	1	0.3	
Level of care need					<0.001
no certified care need	24	36.4	266	84.2	
any level of certified care need	38	57.6	34	10.8	
Current care services					<0.001
No care service	31	47.0	279	88.3	
One or more care services	35	53.0	36	11.4	
Types of care service (Multiple answers)					
home nursing	9	13.6	2	0.6	<0.001*
home help service	11	16.7	5	1.6	<0.001*
home pharmacist	1	1.5	0	0.0	0.173
day care/day service	26	39.4	28	8.9	<0.001
specialized palliative care service	2	3.0	0	0.0	0.030*

*Fisher's exact test

Look for two or more general indicators of deteriorating health

- Performance status is poor or deteriorating (in bed or a chair for ≥50% of the day); reversibility is limited
- Dependent on others for most care needs due to physical or mental health problems
- Two or more unplanned hospital admissions in the past 6 months
- Significant weight loss (5–10%) over the past 3–6 months or a low body mass index
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s)
- Patient asks for supportive and palliative care or treatment withdrawal

Look for any clinical indicators of one or more advanced conditions

Cancer

- Functional ability deteriorating due to progressive metastatic cancer
- Too frail for oncology treatment or treatment is for symptom control

Dementia/frailty

- Unable to dress, walk, or eat without help
- Eating and drinking less or swallowing difficulties
- Urinary and faecal incontinence
- No longer able to communicate using verbal language or little social interaction
- Femur fracture or multiple falls
- Recurrent febrile episodes or infections, or aspiration pneumonia

Neurological diseases

- Progressive deterioration in physical or cognitive function despite optimal therapy
- Speech problems with increasing difficulty communicating or progressive swallowing difficulties
- Recurrent aspiration pneumonia, breathlessness, or respiratory failure

Heart/vascular disease

- NYHA* Class III/IV heart failure or extensive untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion
- Severe inoperable peripheral vascular disease

Respiratory disease

- Severe chronic lung disease with breathlessness at rest or on minimal exertion between exacerbations
- Needs long-term oxygen therapy
- Has needed ventilation for respiratory failure or ventilation is contraindicated

Kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR#< 30 ml/min) with deteriorating health
- Kidney failure complicating other life-limiting conditions or treatments
- Discontinuation of dialysis

Liver disease

- Advanced cirrhosis with one or more complications in the past year:

  Diuretic resistant ascites

  Hepatic encephalopathy

  Hepatorenal syndrome

Bacterial peritonitis

Recurrent variceal bleeding

• Liver transplantation is contraindicated

* NYHA: New York Heart Association

#eGFR: estimated glomerular filtration rate